#### THE WITHDRAWAL OF LIFE SUPPORT TREATMENT AND THE COURTS

## By Una Doherty, Advocate June 2018

The recent case of Alfie Evans was well publicised, as was the case last year of Great Ormand Street Hospital against the parents of a baby, Charlie Gard. Both were English cases which involved the withdrawal of artificial ventilation and the resultant death of the children. There have, however, been no recent reported cases in Scotland on the issue of the withdrawal of life support treatment. This talk will be in five sections:

- 1. The right of patients to consent to treatment and the role of doctor to provide treatment (including the situation when the patient lacks capacity)
- 2. The clinical guidance available which informs the doctor's decision as to the withdrawal of life sustaining treatment
- 3. Decisions in England on withdrawal of life support treatment
- 4. The Scottish position
- 5. Observations

#### 1. The consent process and the doctor's duty to provide treatment

An adult patient with capacity is entitled to consent to or withhold consent to treatment which would have the effect of prolonging his life. In recent years, patient autonomy has become increasingly emphasised. If an adult patient of sound mind refuses to consent to treatment or care which would prolong his life, the doctors responsible for his care must give effect to his wishes even if they do not consider it to be in his best interests to do so<sup>1</sup>.

Although a doctor has a duty to provide treatment for which consent has been given, he cannot be obliged to provide treatment which he considers to be inappropriate and not in the patient's interests. As was said by Baroness Hale in **Montgomery v Lanarkshire Health Board**<sup>2</sup>, the patient "cannot force her doctor to offer treatment which he or she considers futile or inappropriate".

<sup>&</sup>lt;sup>2</sup> [2015] UKSC 11. 2015 SC (UKSC) 63 at [15]



<sup>&</sup>lt;sup>1</sup> Airedale NHS Trust v Bland (HL) 1993 AC 789 at 864

When the patient is a child or an adult who lacks capacity, the position is more complicated. For a child, parents have parental responsibilities which include the right to consent to treatment on behalf of their child, provided the treatment is in the best interests of the child. When the patient is an adult who lacks capacity, he is unable to state whether or not he consents to treatment. The law provides that a doctor may lawfully treat such a patient if it is in the patient's best interests to receive that treatment<sup>3</sup>. In medical practice every day, best interests decisions are routinely made for terminally ill patients who have lost consciousness, for example in a short-lived terminal state of coma, in consultation with those close to the patient and without any recourse to the courts. Specific clinical guidance is given, however, in relation to patients who are in a prolonged disorder of consciousness as I will explain in this talk.

In England, the Mental Capacity Act 2005 provides for decisions being made on behalf of a person who lacks capacity, by persons other than the court. Section 4 sets out the "best interests" test to be applied, and section 5 sets out the circumstances in which a person would avoid liability for acts done in connection with the care or treatment of a person who lacked capacity. The Act does not stipulate that the best interests test has to be determined by the court in every or any particular types of case.

In Scotland the Adults with Incapacity (Scotland) Act 2000 applies. Part 5 of the Act makes provision for medical treatment and deals with issues of consent where the patient lacks capacity. It does not, however, deal expressly with withdrawal of treatment decisions. The view taken by the Mental Welfare Commission is that the Act does not expressly or implicitly deal with withdrawal of treatment decisions, although the issue is untested in the Scottish courts.

Where there is disagreement over the treatment to be given to or withdrawn from a patient who lacks capacity, recourse can be had to the courts. If court proceedings are raised by the health board, this will be to obtain the court's authority to the proposed provision or withdrawal of treatment. The court's decision will give reassurance to all parties. It will protect the health board from potential complains and claims. It will protect the doctors from

<sup>&</sup>lt;sup>3</sup> Airedale NHS Trust v Bland (HL) 1993 AC 789 at 866-867



potential complaints to the GMC, from potential civil claims and from potential criminal charges. This talk focuses on the withdrawal of treatment, but applications to court are also made for declarations that it is in the best interests of a patient to receive life support treatment when this is disputed<sup>4</sup>. Also, applications to withdraw treatment can be made by relatives rather than by the medical authority<sup>5</sup>.

# 2. Clinical guidance on withdrawal of treatment when the patient has a disorder of consciousness

The diagnosis of a disorder of consciousness is complex. These disorders include coma, vegetative state (VS) and minimally conscious state (MCS). It can be difficult accurately to determine which disorder of consciousness is suffered.

In 2013 the Royal College of Physicians (RCP) issued guidelines 'Prolonged disorders of consciousness: National clinical guidelines' which updated existing guidelines and aimed to achieve a more consistent approach to the diagnosis and management of patients with prolonged disorders of consciousness including VS and MCS. A prolonged disorder of consciousness is one where the patient remains in "a state of wakefulness but absent or reduced awareness for more than 4 weeks". This may occur as a result of sudden onset acquired brain injury, advanced dementia or other chronic progressive neurodegenerative disorders. The requirements for assessment and monitoring are different in the context of a known deteriorating trajectory, and the primary focus of these guidelines is on sudden onset acquired brain injury.

The guidelines provide definitions and criteria for the diagnosis of VS and MCS. A patient in a VS is defined as being in a state of wakefulness without awareness in which there is

<sup>&</sup>lt;sup>6</sup> London 2013



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<sup>&</sup>lt;sup>4</sup> A recent example is *Salford Royal NHS Foundation Trust v P* [2017] EWCOP 23, where the court applied for a declaration that it was in the best interests of a 72 year old to receive clinically assisted artificial nutrition and hydration. The patient's family disagreed; their position was that she would not have wanted to be kept alive. The Trust's application was refused.

<sup>&</sup>lt;sup>5</sup> A recent example is *Briggs v Briggs (No.2)* [2016] EWCOP 53, where the wife of a patient in a MCS applied for an order allowing the CANH keeping him alive to be withdrawn. The application was granted.

preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours. Essential criteria for the diagnosis of VS are the absence of evidence of

- awareness of self or environment or the ability to interact with others
- sustained purposeful or voluntary behaviours, either spontaneously or in response to visual, auditory, tactile or noxious stimuli
- language, comprehension or meaningful expression.

MCS is defined as a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated.<sup>8</sup> For the diagnosis to be made, there must be limited but clearly discernible evidence of self or environmental awareness demonstrated on an inconsistent, but reproducible or sustained, basis by one or more of the following behaviours:

- following simple commands
- gestural or verbal 'yes/no' responses (regardless of accuracy)
- intelligible verbalisation (accepting inaccuracy due to specific speech or language deficits)
- purposeful or discriminating behaviour, including movements or affective behaviours that:
  - -occur in contingent relation to relevant environmental stimuli, and
  - -are not due to reflexive activity.

There is a broad spectrum of what amounts to minimal consciousness<sup>9</sup>.

A VS can be regarded as permanent (PVS) after six months where the VS arises from nontraumatic injury, or after one year following traumatic brain injury. Regardless of aetiology, a patient who has been in a continuing MCS for five years with no demonstrable trajectory for improvement may be classified as being in a permanent MCS, but may be classified as permanent in a shorter period in certain circumstances. Recovery from both permanent VS and permanent MCS is regarded as highly improbable. 10

<sup>9</sup> ibid p6-7

<sup>&</sup>lt;sup>10</sup> ibid p10-11



 $<sup>^{7}</sup>$  Royal College of Physicians 'Prolonged Disorders of consciousness: National clinical guidelines' [London 2013] p3-4

<sup>8</sup> ibid p3

### The 2013 guidelines include sections on

- how clinicians should assess, diagnosis and monitor conditions of VS and MVS
- the care pathway from acute to longer term management
- end of life decisions based on the best interests of the patient, and applications to court.

As well as the RCP 2013 guidelines there is General Medical Council (GMC) guidance which remains current: 'Treatment and care towards the end of life: good practice in decision making', This guidance sets out the approach to be taken by the doctor in the case of a patient who lacks capacity. Although there is a presumption in favour of prolonging life, if the doctor considers that treatment would not be clinically appropriate and of overall benefit, he is not required to provide it, and this should be explained to the patient's legal proxy or other person involved in the decision making. In Scotland, there is a further guideline published in March 2013: 'Brain injury rehabilitation in adults: A national clinical guideline', 12.

In December 2017, interim guidance for health professionals in England and Wales was published jointly by the GMC, the RCP and the British Medical Association (BMA), on decisions to withdraw clinically assisted nutrition and hydration (CANH) for patients in permanent VS or MCS following sudden- onset profound brain injury<sup>13</sup>. This interim guidance is supplementary to the existing guidance, and sets out the steps required for a detailed assessment to establish the patient's level of awareness and the prognosis, and the steps required for decisions to withdraw treatment.

#### 3. Decisions in England

#### (i) The requirement for court proceedings

<sup>12</sup> Scottish Health Intercollegiate Network, SIGN 130 March 2013

<sup>&</sup>lt;sup>13</sup> GMC/RCP/BMA 'Decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset profound injury' Interim guidance for health professionals in England and Wales December 2017



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<sup>&</sup>lt;sup>11</sup> Published in May 2010

In England and Wales, there is a Court of Protection created under the Mental Capacity Act 2005. This court has the power to decide if a person lacks capacity to make decisions, and to decide what actions to take in the person's best interests. Prior to this Court of Protection, there was a previous court governed by the Mental Health Act 1983, which formed part of the old Office of Public Guardian.

From 1993 until relatively recently, as a matter of practice in England and Wales all cases of proposed withdrawal or withholding of life sustaining treatment in relation to adults in a PVS or a MCS have been referred to the Court of Protection for it to consider whether the proposed order was justified or not.

This practice arose out of the House of Lords' decision of **Airedale NHS Trust v Bland**<sup>14</sup>, a case which involved a patient who had been in a PVS for more than two years following severe injury. The Trust responsible for the hospital where he was cared for sought a declaration from the court that it was lawful to discontinue all life sustaining treatment and medical treatment designed to keep him alive, in particular artificial feeding and antibiotics. The patient's family concurred with the application. The application was granted by the court. There was an appeal by the Official Solicitor to the Court of Appeal and then to the House of Lords. The House of Lords concluded that as a large body of informed and medical opinion was of the view that existence in PVS was not a benefit to the patient, the principle of the sanctity of life was not violated by ceasing to give medical treatment and care. There was no prospect of recovery and further treatment was futile. Lord Keith of Kinkell explained <sup>15</sup>:

"Although this case falls to be decided by the law of England, it is of some comfort to observe that in other common law jurisdictions, particularly in the United States where there are many cases on the subject, the courts have with near unanimity concluded that it is not unlawful to discontinue medical treatment and care, including artificial feeding, of P.V.S. patients and others in similar conditions.

The decision whether or not the continued treatment and care of a P.V.S. patient confers any benefit on him is essentially one for the practitioners in charge of his case. The question is whether any decision that it does not and that the treatment and care should therefore be discontinued should as a matter of routine be brought before the Family Division for endorsement or the reverse. The view taken by the President of the Family Division and the

<sup>&</sup>lt;sup>15</sup> ibid at 859



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<sup>&</sup>lt;sup>14</sup> 1993 AC 789

Court of Appeal was that it should, at least for the time being and until a body of experience and practice has been built up which might obviate the need for application in every case. As Sir Thomas Bingham M.R. said, this would be in the interests of the protection of patients, the protection of doctors, the reassurance of the patients' families and the reassurance of the public. I respectfully agree that these considerations render desirable the practice of application."

It has been suggested that the House of Lords may have decided on a routine review of all decisions to withdraw CANH from PVS patients because (1) this was the first time the courts had considered whether CANH was actually a form of medical treatment rather than a facet of basic care, and (2) with CANH the patient could have survived in his PVS for many years, but withdrawal would result in speedy death<sup>16</sup>.

As a result of this decision in 1993, until recently in England the courts have reviewed all cases of stopping feeding and hydration in patients with a prolonged disorder of consciousness. The Court of Protection issued a Practice Directive in 2007 updated in 2015 (PD9E), which provided that decisions about serious medical treatment, specifically including but not limited to the proposed withdrawal of artificial nutrition and hydration, from a person in a PVS or a MCS were to be brought before the court. This amounted to an extension of the need for court approval beyond the cases of PVS stipulated in **Airedale** to cases of MCS, even although practice directions do not create substantive legal obligations<sup>17</sup>.

The BMA, the RCP and the GMC all issued guidance that an application to the Court of Protection should be made in all cases where it was intended to withdraw CANH from patients in PVS or MSC following sudden onset profound brain injury. The guidance was specific to the withdrawal of CANH from those two categories of patients.

For many years, therefore, applications to the Court of Protection were made in these cases even when there was no disagreement or uncertainty about withdrawing treatment from the patient. There was growing concern over the rationale for this necessity to apply to court, not least because of the time, energy and cost involved in seeking a court declaration.

The position changed in 2017, when the court held that there was no legal requirement to

<sup>&</sup>lt;sup>17</sup> NHS Trust v Y (by his Litigation Friend) [2017] EWHC 2866 (QB) at [33]



<sup>&</sup>lt;sup>16</sup> English V, Sheather JC 'Withdrawing clinically assisted nutrition and hydration (CANH) in patients with prolonged disorders of consciousness: is there still a role for the courts?'. J Med Ethics 2017 0:1-5

seek a court order in these circumstances, rather it was just a matter of practice. In **M** (**Incapacitated Person**): **Withdrawal of Treatment**<sup>18</sup>, the Court of Protection was asked to determine if it would be in the best interests of a patient in a MCS not to continue to receive CANH with the result that she would die. The application was supported by her family, clinicians and by specialist opinion. The court was satisfied that it was not in the patient's best interests for her life to be continued by CANH. It stated that on the facts of the case there was no legal requirement for the decision to withdraw CANH to be taken by the court, where the clinicians have followed good medical practice, there was no dispute with the family of the patient who lacked capacity, and no other doubts or concerns.<sup>19</sup>

This view was followed in November 2017 by the Queen's Bench Division in NHS Trust v Y (by his Litigation Friend)<sup>20</sup>, where the court declared that it was not mandatory to seek the court's consent to the withdrawal of CANH from a patient who had a prolonged disorder of consciousness, where the clinical team and the patient's family were agreed that it was not in his best interests to continue to receive that treatment. The patient had suffered extensive brain damage as a result of severe hypoxia due to a cardiac arrest. It was highly improbable that he would re-emerge into consciousness. The Trust argued that there was no statutory or common law obligation to refer the decision to the court where there was no dispute as to the patient's best interests. The Official Solicitor, appointed to act on the patient's behalf and represent his best interests, argued that although there was no statutory obligation to bring the application before the court, there was a common law obligation to do so to ensure that his rights under ECHR Articles 2 and 6 were not infringed, and to provide independent scrutiny of the decision. The court rejected the Official Solicitor's argument. The Official Solicitor applied for permission to appeal directly to the Supreme Court, and that application was granted. The appeal was heard by the Supreme Court in February 2018 but no decision has yet been issued.

The Court of Protection's Practice Directive 9E was repealed on 1 December 2017. No comparable directive which relates to the withdrawal of treatment has been issued, and there is no indication that it is proposed to replace it. The interim guidance for health professionals in England and Wales published jointly in December 2017 by the GMC, the RCP and the BMA which I have already mentioned, advised that providing existing clinical guidance had

<sup>18</sup> [2017] EWCOP 19

<sup>20</sup> [2017] EWHC 2866 (QB)



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<sup>&</sup>lt;sup>19</sup> [2017] EWCOP 19 at [37]- [38]

been followed and all relevant parties agreed that it was not in the patient's best interests to continue with CANH treatment, good clinical practice did not require that court approval be sought before CANH could lawfully be withdrawn from patients in PVS and MCS.

#### (ii) Best interests test

Given the procedural direction which existed in England until last year which required all applications for withdrawal of serious medical treatment in PVS and MCS cases to be made to a court, there have been many court decisions in England considering the issue of whether or not the withdrawal of treatment was in the patient's best interests, on the particular facts of each case.

Helpful statements on what requires to be considered in assessing a patient's best interests were given by the Supreme Court in 2013 in the case of **Aintree University Hospitals NHS Foundation Trust v James<sup>21</sup>**. The patient was in a MCS and the Trust sought declarations in support of withholding certain life-sustaining treatment should his condition deteriorate further so that such treatment became necessary. The Court of Protection refused the application, but there was a successful appeal to the Court of Appeal, and then to the Supreme Court which upheld the Court of Appeal decision. Baroness Hale said:

"[22]...the focus is on whether it is in the patient's best interest to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it...

[35] The authorities are all agreed that the starting point is a strong presumption that it is in a person's best interests to stay alive. As Sir Thomas Bingham MR said in the Court of Appeal in **Bland**, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy". Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive lifesustaining treatment.

[36] The courts have been most reluctant to lay down general principles which might guide the decision. Every patient, and every case, is different and must be decided on its own facts. As Hedley J wisely put it at first instance in **Portsmouth Hospitals NHS Tryst v Wyatt** 

<sup>&</sup>lt;sup>21</sup> [2013] UKSC 67



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[2005] 1FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as **Bland**, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time...

"[39]...in considering the best interests of this particular patient at this particular time, decision- makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

Baroness Hale went on to say that the purpose of the best interests test is to consider matters from the patient's point of view. Where a patient is suffering from an incurable disability, the question is whether the patient would return to a quality of life he or she would regard as worthwhile<sup>22</sup>.

In Great Ormand Street Hospital for Children NHS Foundation Trust v Yates<sup>23</sup>, the Trust sought a declaration that it was in Charlie Gard's best interests for artificial ventilation to be withdrawn and for him to be given only palliative care. Charlie was a baby with a rare progressive condition: mitochondrial depletion syndrome. This condition left him unable to move his limbs or to breathe unaided. His organs were affected, he was deaf, suffered epileptic fits and was severely brain damaged. Charlie's parents opposed the application, as they wanted Charlie to undergo experimental therapy in America. The Trust succeeded in obtaining a declaration from the court in April 2017. The court agreed with the Trust that therapy would only prolong Charlie's suffering, that treatment was futile and not in Charlie's best interests. The court concluded that neither the experimental therapy nor continued ventilation was in Charlie's best interests, and ventilation could be withdrawn.

Charlie's parents appealed that decision. The Court of Appeal<sup>24</sup> dismissed the appeal and affirmed the long-established position that while parents have power to make many decisions on behalf of their children, where there is debate between medical professionals and parents, it is the court that decides, on the basis of what is in the child's best interests assessed in the

<sup>&</sup>lt;sup>24</sup> [2017] EWCA Civ 410



<sup>&</sup>lt;sup>22</sup> ibid at [44]- [45]

<sup>&</sup>lt;sup>23</sup> [2017] EWHC 972

widest sense. The Court found that the judge at first instance had been entitled to make the findings which he had. Charlie's parents sought permission to appeal to the Supreme Court, but permission was refused<sup>25</sup>. The Court confirmed that where there is a dispute about a child's welfare, it must be resolved by reference to the child's best interests; the child's rights rather than the parents' were of paramount consideration. The judge had made findings in fact which could not be challenged, he had applied the correct test, and the case did not raise an arguable point of law of general importance.

Both the Court of Appeal and the Supreme Court were clear that they retained decision making authority where the welfare of the child was at issue, rather than the parents having the final say. They were prepared to authorise the withdrawing of artificial ventilation, in Charlie's best interests. Charlie's parents made an application to the ECHR, claiming that there had been a violation of their and Charlie's Article 2 right to life, a violation of Charlie's Article 5 right to liberty, an interference with their Article 8 rights to respect for private and family life, and a violation of their Article 6 right by the Court of Appeal which had not heard evidence in deciding the question of significant harm. The ECHR found all arguments to be unfounded<sup>26</sup>.

Another recent high profile case related to the proposed withdrawal of ventilator support from Alfie Evans. In **Alder Hey Children's NHS Foundation Trust** v **Evans<sup>27</sup>**, the Trust applied for a declaration that continued ventilator support was not in 21-month- old Alfie Evan's best interests, and so it was not lawful for such treatment to continue. Alfie had been diagnosed with a rapidly progressive destructive brain disease. He was in a coma and required ventilation and intensive care. The medical evidence was that treatment for Alfie was futile. It was possible that he continued to experience pain. Alfie's parents wanted to take him to Rome for further treatment there, although no new treatment was offered. The court referred to and was guided by the best interests of the child approach, as set out in **Aintree.** It was satisfied that the continued provision of ventilation in circumstances which were futile compromised Alfie's dignity and failed to respect his autonomy. It therefore granted the

<sup>&</sup>lt;sup>26</sup> Charlie Gard and Others v United Kingdom Application no. 39793/it 17, 28 June 2017 [2018] EWHC 308 (Fam)



<sup>&</sup>lt;sup>25</sup> 'In the matter of Charlie Gard, Determination of Permission to Appeal Hearing', 8 June 2017 UKSC website

Trust's application<sup>28</sup>. There was an unsuccessful appeal to the Court of Appeal (argued on one ground only), and then an unsuccessful application to appeal to the Supreme Court. The Supreme Court gave detailed reasons for its refusal of permission to appeal, which included a statement by the Court that "the current law of England and Wales is that decisions about the medical treatment of children, like those about the medical treatment of adults, are governed by what is in their best interests "29. The parents made an application to the ECHR which was also unsuccessful.

The parents then made an application for a writ of habeas corpus, on the basis that Alfie was being unlawfully detained in hospital. That application was rejected as being entirely misconceived. There was an appeal to the Court of Appeal, which was dismissed. The Court of Appeal reiterated that the decision as to Alfie's best interests must be governed by an objective assessment<sup>30</sup>.

There was then another application by Alfie's parents, who argued that there had been a change of circumstances since the initial decision February 2018. On 23 April 2018 Alfie had been extubated and was still breathing; he could be taken by military air ambulance, which was on standby, to a children's hospital in Rome. The court rejected the argument that there was a change of circumstances<sup>31</sup>. Alfie's parents applied for permission to appeal against this judgment but permission was refused on the basis of no reasonable prospects of success<sup>32</sup>. Alfie died on 28 April 2018.

Both the Charlie Gard and the Alfie Evans' cases can be contrasted with the position in many PVS and MCS cases, as both children had swiftly progressive conditions. By contrast, in many n PVS and MCS cases death may not be imminent and patients may live for many years.

#### 4. The position in Scotland

<sup>&</sup>lt;sup>32</sup> [2018] EWCA Civ 984



<sup>&</sup>lt;sup>28</sup> ibid at [66]. At [52], the court also quoted from an open letter by Pope Francis to the President of the Pontifical Academy for Life dated November 2017, in which Pope Francis called for greater wisdom in striking a balance between medical efforts to prolong life and the responsible decision to withhold treatment when death becomes inevitable.

<sup>&</sup>lt;sup>29</sup> Supreme Court 20 March 2018 at [17], quoted in [2018] EWCA Civ 805

<sup>&</sup>lt;sup>30</sup> [2018] EWCA Civ 805 at [67]

<sup>&</sup>lt;sup>31</sup> [2018] EWHC 953 (Fam)

In contrast to the position in England, there have been few court actions on the issue of withdrawing life support treatment from a patient who does not have capacity. The last reported Scottish case is **Law Hospital NHS Trust v Lord Advocate**<sup>33</sup>. The patient was in a PVS for around four years, and was kept alive through artificial feeding and hydration along with nursing care she received in hospital. There was no prospect of improvement in her condition. If nutrition and hydration treatments were withdrawn, she would die within 10-14 days. The Trust sought a declarator that all life-sustaining and medical treatments might lawfully be discontinued and that thereafter no such treatment need be provided except for the sole purpose of allowing her to die peacefully with dignity and with the least distress. The medical staff and the patient's family all agreed with this course of action. There was a proof before the Lord Ordinary who reported the matter to the Inner House for guidance. The Inner House relied on and quoted from the English authorities, particularly **Airedale NHS Trust v Bland**<sup>34</sup>. The Inner House stated that the test to be applied was whether the proposed course was in the best interests of the patient. Lord President Hope said:

"The question is whether the continuance of the treatment can be of any benefit to the patient in view of the condition which she has now reached. If it is possible to say that it can be of any benefit to her, then no doubt there is a balancing exercise to be done in order to assess whether it is in her best interests that the treatment should be discontinued. But if it cannot be of any benefit to her...then there are no longer any best interests to be served by continuing it." <sup>335</sup>

The Inner House also stated that the decision whether an application would be necessary where it was intended to withdraw treatment had to rest in each case with those responsible for carrying the intention into effect, having regard in particular to the views of the patient's relatives and any statements of policy which might be issued by the Lord Advocate.

When the Lord Ordinary resumed consideration of the case, having obtained the Inner House's guidance, he was satisfied that there were no longer benefits to the patient in continuing her treatment and he granted an order authorising discontinuance of treatment<sup>36</sup>.

The Lord Advocate issued a statement of policy on 11 April 1996, in light of the views of the Inner House:

<sup>&</sup>lt;sup>36</sup> 1996 SLT 869



<sup>&</sup>lt;sup>33</sup> 1996 SC 301 and Law Hospital NHS Trust v Lord Advocate (No. 2) 1996 SLT 869

<sup>&</sup>lt;sup>34</sup> 1993 AC 789

<sup>35 1996</sup> SC 301 at 317

"The Lord Advocate has decided that he will not authorise the prosecution of a qualified medical practitioner (or any other person acting upon the instructions of such a practitioner) who, acting in good faith and with the authority of the Court of Session, withdraws or otherwise causes to be discontinued life-sustaining treatment or other medical treatment from a patient in a persistent, or permanent, vegetative state, with the result that the patient dies." <sup>37</sup>

Recent guidance issued by the COPFS suggests that the Lord Advocate's position on this remains the same, so there will not be a prosecution if the medical practitioner acts in good faith and with the authority of the court. The Guidance also states that although immunity from prosecution does not automatically extend to medical practitioners who withdraw life sustaining treatment from patients in a persistent or permanent vegetative state so that the patient dies, if the doctors were acting in accordance with accepted medical practice and with the proper degree of care expected of them, it would be very unlikely that any prosecution would be brought against them<sup>38</sup>.

Since the **Law Hospital** case, there have been only been a few similar Scottish court actions, none of which have resulted in a reported decision.

Importantly, in the Inner House decision in **Law Hospital**, Lord President Hope set out the procedural requirements of future similar applications including the need to proceed by a petition, lodging with the petition two expert medical reports and the appointment by the court of a curator *ad litem* to the patient<sup>39</sup>. The current Rules of Court provide for such petitions to be raised under Rule 14.2(i), and the annotations to the Rules set out the procedural requirements stipulated by Lord President Hope.

#### 5. Observations

As already noted, there are have been few Scottish cases on the issue of withdrawal of life support treatment, compared to in England. There may be several reasons for this

• the small size of the Scottish jurisdiction

<sup>&</sup>lt;sup>38</sup> 'Reporting Deaths to the Procurator Fiscal, Information and Guidance for Medical Practitioners' COPFS 2015





<sup>&</sup>lt;sup>37</sup> Reproduced in 1996 SCLR 491 at 519

- poor access to legal funding for potential challenges to medical decisions
- the lack of an equivalent to the Court of Protection or a procedural direction such as
  that which existed until earlier this year in England which required applications for
  withdrawal of supportive treatment in PVS and MSC cases to be made to a court
- a willingness by doctors to proceed without prior court approval.

It is anticipated that the Scottish courts will refer to and be guided by the English cases since the **Law Hospital** case in 1996.

The general approach from the authorities is to start from the presumption that it is in a patient's interests to continue to live, so acts by clinicians which will end or threaten life require justification. The potential for civil or criminal complaints remains, if life support treatment is withdrawn from patients in a VS or a MCS without the authorisation of a court order. For that reason, as a matter of practice, where medical guidance has been complied with and the view reached by clinicians is that treatment should be withdrawn, express agreement is sought from other involved parties such as relatives that the withdrawal is in the patient's best interests. Presumably this is done on the basis that it would not be lawful for the clinicians to carry on with treatment which they consider is against the patient's best interests. As noted previously, there is significant guidance for clinicians as to the best clinical practice for the diagnosis, care and treatment of patients with prolonged disorders of consciousness, which includes involving families. In most cases, it should be possible to reach agreement.

It is likely that there will continue to be some cases where agreement cannot be reached, possibly due to different views of the medical situation and potential treatment, or different views of the patient's quality of life and the value of maintaining that life. Mediation has been suggested as a way of resolving such disagreements, rather than applications to the court. Medition could potentially enable a better understanding of the facts which support the decision to withdraw treatment, in particular cases, and so lead to ultimate agreement of the decision. Otherwise, it is difficult to see how mediation could ever lead to a resolution of a fundamental dispute over withdrawal of treatment.



If agreement cannot be obtained, then the clinicians / health boards understandably feel the need to protect their positions by making an application to the court. This has not occurred often to date in Scotland. I mention again, however, that the Supreme Court's decision in the appeal NHS Trust v Y (by his Litigation Friend) is awaited. The Supreme Court requires to decide on the appellant's argument that there is a common law obligation to bring before the court the proposed withdrawal of CANH from a patient who has a prolonged disorder of consciousness, to ensure that his rights under ECHR Articles 2 and 6 are not infringed and to provide independent scrutiny. If the Supreme Court supports this argument, I would expect this to have ramifications for the court's involvement in the withdrawal of other life supporting treatment. Potentially, even in cases where there is no disagreement that it is in the patient's best interests for life supporting treatment to be withdrawn, the court would still require to scrutinise the clinicians' decision without there being a contradictor, with the delay and expense involved in that process.

When the court's involvement is sought currently, that can result in significant delay in the withdrawal of treatment. In the case of Charlie Gard, the various court proceedings took five months - his parents were convinced that had the alternative therapy they suggested been administered during this period, Charlie's condition would not have deteriorated so that by July 2017 it was too late to be of any benefit. The court proceedings in the Alfie Evans case also took about five months. Both did have a number of applications and appeals, so in England at least a initial application can be dealt with in a shorter timescale.

In Scotland, there is no special expedited procedure for this kind of petition. The rules require service of the petition, time for answers and the appointment of a curator *ad litem* who will undertake what inquiries he considers appropriate. The court will then order whatever form of hearing is required. The process may take several months, during which time the patient will continue to receive treatment which the clinicians consider is not in his best interests. An expedited procedure would be desirable, although it may be unlikely that such a procedure will be put in place unless there is a significant increase in the number of such petitions.

